Immunocompromised Passports

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Immunocompromised Passports

Being muted in the pandemic is manifested in the Zoom calls or Google Meets where the moderator reminds you time and again that your open mic causes interference, and a good participant is a silent one. Those of us who spend our days in our remote worlds are quickly becoming accustomed to being silent, or at least we have become accustomed to the expectation of our silence: to seeing our voice (or the voice of someone else) as intrusive. The online meeting is a metaphor, or a manifestation, of other ways the pandemic causes us to mute each other. This is a unique period in which we seem to demand participation and silence at the same time. We want to come together, silently, and at least six feet apart. And preferably outdoors. Unless it’s cold and raining, in which case we don’t want to come together at all.

We mute others when we deny there is a pandemic. Or when we declare our fed-upness with the pandemic. When we insist the pandemic is nothing but hardship for everyone, and anyone not suffering is in denial or too privileged and self-absorbed. We mute ourselves when we luxuriate as introverts in isolation, and ignore the deteriorating mental health of our neighboring extroverts. Or, when we forget that “essential worker” is the person who works at the gas station or the grocery store. Or, by insisting we must all be paralyzed by the pandemic. In fact, in our quixotic attempts to unify behind a common cause, in trying to determine and fix a shared pandemic experience, we overlook the capricious nature of illness.

The immunocompromised and their families are familiar with this unpredictability. My husband has a significantly impaired immune system. It barely works. Except when it does, which is why words like “idiopathic” or “variable” keep cropping up in his medical files. For the immunocompromised, the pandemic, while wreaking economic and personal hardship, normalizes some things we’ve longed to do. Like tell everyone to wear masks or go away.

For a moment, one can imagine that suddenly the public at large gets how vulnerable we all are, immunocompromised or not, to fickle, invisible germs. Discussions around who is most vulnerable to COVID-19 have moved immune disorders or those with “orphan diseases” out of the shadowy recesses of the public unconscious, to be greeted with, if not empathy, at least a kernel of recognition in the face of a global health crisis. The pandemic means that folks suddenly understand a little more about what it might mean to have an illness that isn’t readily apparent. The idea that you could be asymptomatic and spreading disease like Typhoid Mary frightens people; even more frightening is the thought
that the healthy-looking person next to you could be Typhoid Mary. Now, with the pandemic, I can put a sign on my front door that reads, “Masks required! Immunocompromised person lives here!” A year and a half ago, this would have felt awkward, but now, not so much. There is guilt over feeling grateful for this ironic breather.

Unfortunately, for a culture preoccupied with metaphors of illness as a battle (singular) that must be either fought and won or fought and lost, “pandemic fatigue,” like its relatives, “battle fatigue” and “compassion fatigue” soon mutes the immunocompromised and their newly discovered cousins, the “long-haulers,” who are reminders that illness is complicated and nonlinear. “It seems strange that the language of healing remains so interwoven with the language of warfare” writes Dhruv Khullar in an essay about cancer, “especially in the era of chronic disease, when many conditions are controlled and managed, not eradicated or annihilated”(Khullar). Despite Khullar’s sensible critique on language, we persist in this warmongering. A recent headline from CBS News proclaims, “Biden Rolls Out Plan to Battle Coronavirus Pandemic with New Executive Orders” (“Biden”). Here, the battle metaphor seems appropriate, as Biden (like his predecessor) will use the Defense Production Act, a federal law enacted during the Cold War, to aid in the production of vaccines and COVID-19 tests.

As people complain about being so tired of dealing with COVID-19, I think of all the caretakers who are so tired of all the chronic and long-term illnesses we’ve been handling with loved ones, from dementia to multiple sclerosis to autoimmune disorders to mysterious conditions that defy diagnoses. For these caretakers, we will feel lucky if that weariness, which started years before COVID-19, continues; it will mean loved ones are still alive to fight for. But with that weariness comes a flood of what-ifs: what if I bring it home on my clothes? What if I touch a door handle and absentmindedly adjust my glasses and then later, at home, touch my glasses and don’t wash my hands and then touch my eyes? In an essay about returning to Greece to care for his elderly mother, novelist and playwright Gianni Skaragas contemplates his role as caretaker, “We are the main characters in our private dystopian sci-fi stories, aware that our alertness is a determining factor for the health of the most vulnerable people among us” (61). In my dystopian story, while the recent research has said there is a low risk of SARS-CoV-2 transmission by fomites, I still find myself compulsively wiping down groceries and door knobs.\(^1\) My sci-fi world is one built around “what ifs,” because “low risk” does not equate to “no risk.” But then this vigilance and its

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\(^1\) Several studies indicate low risk of fomite transmission for SARS-CoV-2. See Mandelli, Colaneri, Seminari, Baldanti, and Bruno for an overview of the findings.
alarms are familiar characters in my narratives: over the years, every flu season, they raise their eyebrows in warning every time one of my students politely covers their cough with their essay and then hands it to me.

Through the lens of jealousy and bitterness, I marvel at those who have the luxury of denying the pandemic as they decry mask-wearing people like myself as dupes for a government plot to take away civil liberties. I marvel at the healthy people who stumble around in such shock that they could get rapidly ill, aware for the first time of the fragility of their health. I particularly struggle, though, when I see a neighbor’s maskless family gathering, and I wonder how it is we can live in separate universes. This, I think, is the most dystopian moment of them all.

Whether manifesting as dystopian novels or war, metaphors are an inherent part of medicine and illness. In a commentary on Susan Sontag’s seminal book, Illness as Metaphor, Shirin Karimi writes that while the patient embarks on a journey through illness, the caregiver also “must assume a new passport” to partake of the journey (887). I would extend that even further to the entire family. For the families of people with long-term illness, or the immunocompromised, the pandemic amounts to just another metaphorical stamp in the passport of an arduous--and silent--journey. One day, COVID-19 will be managed globally, and much of the population will likely return to some semblance of unmasked normalcy. For the immunocompromised and their families, this likely means, passport in hand, a return to the muted state.

Works Cited


